

Vulvar Vestibulitis Syndrome: A Review

By **Miranda A. Farage, PhD and Rudolf P. Galask, MD**

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Differential Diagnosis

The differential diagnosis of vulvar vestibulitis syndrome (VVS) can be difficult, which often leads to diagnostic delays. The hallmark characteristics of VVS are the character of the pain (raw, burning pain or sharp, knife-like pain), its localization (confined to the vulvar vestibule), and its elicitation (in response to touch or pressure). Thus, VVS differs from dysesthetic (generalized) vulvodynia, which involves chronic, often non-localized vulvar pain that occurs with or without stimulation. These two vulvar pain syndromes are distinguished from other disorders such as contact dermatitis, the vulvar dermatoses, and acute vulvovaginal infection by

minimal clinical findings (i.e., visual and microscopic), other than the symptom of pain with an unexplained cause.

Other organic causes of vulvar pain must be ruled out before establishing the diagnosis of VVS. Itch is not a symptom of VVS, hence, the absence of vulvar itch is a distinguishing characteristic from acute vulvovaginal candidiasis (yeast infection), allergic contact dermatitis, and skin diseases such as lichen simplex chronicus, lichen sclerosus and lichen planus. The absence of skin or mucosal lesions, or of visual signs of inflammation other than mild vestibular erythema (redness), also dis-

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Sex Therapy in the Treatment of Vulvodynia

By **Stephanie Buehler, PsyD, CST and Christine Seeberger, MA**

Dr. Buehler is a licensed psychologist and certified sex therapist, and the director of The Buehler Institute in Irvine, California. Christine Seeberger has a Master's degree in clinical psychology and is currently researching chronic pelvic conditions in women.

Before vulvodynia became the subject of scientific research, it was often characterized as a psychogenic condition, leading women to struggle with the attitude, "It's all in your head." In the past decade, research has largely dismissed psychogenic factors, and instead proposed alternative explanations, including (i) the characterization of vulvodynia as a pain disorder in which nerves are damaged and pain feedback loops disturbed (Wesselmann, 2001) and (ii) the role of pelvic floor muscle dysfunction as a contributing factor in vulvodynia. These recent conceptualizations, however, can lead practitioners to lean completely in the other direction, focusing solely on the physical treatment of these disorders. Recent advances

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tinguish VVS (and dysesthetic vulvodynia) from contact dermatitis, lichen simplex chronicus, lichen sclerosus, erosive lichen planus and genital herpes simplex.

Microscopic findings help to exclude infectious vulvitis. Patch testing with standard allergens is not recommended unless allergic contact dermatitis (delayed contact hypersensitivity) is suspected in the differential diagnosis; no relevant reactions either to standard allergens or to a series pertinent to perianal or vulvar disorders were found in VVS patients. However, a subset of women with VVS exhibited immediate-type hypersensitivity to seminal fluid, as assessed by their plasma antibody titers to pooled semen samples. A majority of these patients reported that their symptoms began with an episode of sexual intercourse, and that they experienced symptoms only during and after intercourse. Hence, allergy to a component of seminal fluid may be an unrecognized contributing or exacerbating factor in some cases of VVS.

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The National Vulvodynia Association is an educational, nonprofit organization founded to disseminate information on treatment options for vulvodynia. The NVA recommends that you consult your own health care practitioner to determine which course of treatment or medication is appropriate for you.

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Traditionally, histopathology (microscopic examination of tissue) has been of little value except to exclude other conditions. The inflammatory nature of this syndrome is the subject of debate; a nonspecific inflammatory infiltrate is observed in the tissue surrounding the vestibular glands, but this is also seen in normal tissue. Recently, computerized image analysis of immunostained biopsy samples has demonstrated that the number of degranulated mast cells (white blood cells that cause inflammation) localized to the minor vestibular glands, and the overall heightened innervation (nerve density) of the tissue, are distinguishing factors in patients with severe VVS.

Etiology

The etiology (cause) of VVS is unknown. A perplexing array of variables has been associated with the condition, suggesting that multiple factors play a role in the development of VVS.

Neuropathy Secondary to Inflammation

The prevailing theory is that VVS is a neuropathic disorder involving abnormal pain perception; some researchers propose that it results from the sensitization of vestibular nerve fibers and the establishment of a sympathetically maintained pain loop. In this theory, unidentified trigger events (presumably some form of chronic inflammation) activate and cause prolonged firing of the sympathetic Type C nerve fibers responsible for transmitting noxious chemical or thermal stimuli to the brain; this in turn causes certain neurons in the brain to respond abnormally, such that mild stimuli are perceived as pain. This process has been suggested to first result in the localized pain of VVS then progress to the chronic, generalized vulvar pain of dysesthetic vulvodynia.

Several lines of investigation support a neuropathic, or nerve damage, etiology for VVS. Consistent with other neuropathic syndromes, pain thresholds to thermal and mechanical stimuli are lower in VVS patients. The affected tissue is extremely sensitive, i.e., hyperalgesic, to thermal,

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tactile, and pressure stimuli, sometimes involving “after pain” that lasts for minutes after removal of the stimulus. Neuronal hyperplasia, or overgrowth of nerve fibers, may be observed in the most afflicted areas of vestibular tissue. Neurochemical characterization of these free nerve endings indicates that they are nociceptors, i.e., nerve endings responsible for transmitting noxious stimuli to the brain. Doppler perfusion imaging has revealed heightened erythema (redness) and increased superficial blood flow in the posterior vestibule of VVS patients, which suggests either the presence of classic inflammation or neurogenically induced vasodilation (increased blood flow caused by changes in the nervous system).

Recent evidence highlights a potential genetic predisposition to chronic inflammation among VVS-afflicted women. Pro-inflammatory variants of two genes, the interleukin-1 receptor antagonist gene and the melanocortin-1 receptor gene, are substantially more prevalent in VVS patients. The risk of VVS rises additively in women who carry pro-inflammatory variants of both genes. Homozygosity (possessing two identical forms) of allele 2 of the interleukin-1 receptor antagonist gene leads to a reduced capacity to terminate an inflammatory response. Notably, markedly reduced induction of interleukin-1 receptor antagonist was observed in the blood of VVS patients compared to controls.

Unrelated to the above-mentioned genotypes, another subset of VVS patients may be deficient in interferon- α (a protein involved in regulating the immune system) which may contribute to chronic vestibular inflammation by reducing these patients’ ability to combat intracellular infection. Some VVS patients have impaired natural killer cell function, which is involved in tumor surveillance and antiviral immune activity. (Killer cells are white blood cells that attack tumor cells and body cells invaded by foreign substances.) Studies have also demonstrated significantly reduced estrogen receptor expression in localized regions of the vestibular mucosa from VVS patients. Because estrogen both stimulates the antibody response and inhibits inflammation mediated by t-cells (white blood cells critical to the immune response), localized insensitivity to circulating estrogen may increase vulvar

susceptibility to inflammation caused by infectious agents. Although these lines of evidence support a pathogenic role for inflammation, they do not establish a causative relationship between inflammation and neuropathic changes such as nociceptor sensitization (increased sensitivity of nerve fibers that cause pain) and/or increased nerve fiber density. Associations between an altered pattern of innervation (nerve distribution) of the posterior vestibule and local tissue inflammation are suggestive.

Conversely, other researchers have found no evidence for active tissue inflammation in VVS patients, as assessed by inflammatory markers (cyclooxygenase-2 and inducible nitric oxide synthase) that are usually upregulated during the inflammatory process. A complicating factor in identifying possible inflammatory triggers is the delay between first onset of symptoms and first diagnosis; inflammation associated with an initiating event either may subside by the time patients are evaluated or may persist only in the most severe cases.

Infection

A history of genital infections is a risk factor for VVS. Early causative hypotheses focused on epidemiologic links to vulvovaginal candidiasis and genital human papilloma virus (HPV) infection. One study reported a history of recurrent Candida in 80 percent of VVS cases; others found the prevalence of Candida infection to be within the range found in normal subjects. The diagnosis of candidiasis in the aforementioned studies was often presumptive; hence, early misdiagnosis of VVS as candidiasis could have contributed to the observed statistical linkage. More recent investigations, which corroborated referring physician statements or prior laboratory results with patient reports, found VVS risk associated with a history of bacterial vaginosis, *Candida albicans*, pelvic inflammatory disease, trichomoniasis and vulvar dysplasia (precancerous lesions).

The epidemiological association with HPV has been controversial. Studies investigating this hypothesis (most of which examined a limited number

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of viral subtypes) have produced mixed, but mostly negative, results. Laser or cryogenic treatment for prior HPV also has been suggested as a possible precipitating factor for VVS. Recent case-control studies utilizing physician-reported diagnoses found no increased risk associated with prior HPV infection, genital warts, chlamydia, genital herpes or gonorrhea. Emerging data on host factors, such as reduced immune cell function and genetic susceptibility to chronic inflammation, support the hypothesis that either bacterial or viral infections or other potential inflammatory triggers (exposure to noxious chemicals, laser treatment or semen allergy) may play a role in the development of VVS.

Physical Causes

Dysfunction of pelvic floor muscles may be a component of VVS. The variables of pelvic floor muscle instability at rest, elevated resting baseline electromyographic response, and poor muscle recovery after contraction differentiated VVS-afflicted women from controls. Such studies do not distinguish whether these variations of pelvic floor muscular responses are predisposing or causative factors, or consequences of the syndrome.

Diet

Urinary excretion of oxalates, which cause burning and itching of the urethra, was proposed as a contributing factor based on a case report of symptom relief in a single patient whose symptoms were associated with hyperoxaluria (increased oxalates) and elevated urine pH. This etiologic theory was bolstered by the association of VVS and interstitial cystitis; both the vulvar vestibule and the urinary bladder are derived from the same embryologic cells and innervated by branches of the same nerves, suggesting the potential for a shared pathogenesis. However, a prospective study of low oxalate diets in 130 patients and 23 controls failed to confirm therapeutic efficacy.

Psychosexual Dysfunction

Multiple studies have examined the potential etiologic role of psychosexual factors. Women with VVS experience greater psychological distress and

sexual dissatisfaction than healthy controls. Although some investigators propose that the syndrome has a psychogenic origin, the majority dispute this, pointing to evidence of pain relief by surgical excision of affected portions of the vestibule. Studies of the prevalence of psychological distress fail to distinguish whether such impairment is predisposing, precipitating, perpetuating, or simply the result of having an unmitigated pain syndrome. Qualitative research, which examines patients' commentary as an adjunct to standardized psychological profiling, suggests that sexual dysfunction and psychological distress are the consequences of, rather than the cause of, VVS. For example, when asked about the impact of the disorder, VVS sufferers reported dramatic negative effects on sexuality, intimate relationships and psychological well-being which bore no correlation with how they rated such factors prior to symptom onset. Changes associated with disease onset included reduced sexual interest, satisfaction, and willingness to engage in sexual or noncoital intimacy, along with high levels of frustration and increased symptoms of clinical depression. Therefore, optimal treatments must address both physical and psychological components of VVS.

Management

No accepted curative therapy exists and current approaches to management lack clear etiologic bases, i.e., treatment is not directed at a known cause. A dearth of rigorous, randomized prospective trials exists for most therapies; evidence for their efficacy derives largely from single case studies or case series in which each patient served as her control. Studies also differed in the definition of success criteria, including the endpoints assessed (e.g., pain, dyspareunia, sexual function), the extent of recovery (e.g., partial or significant improvement, complete remission) and the duration of follow-up.

Interventions include symptom relief, biofeedback, pharmacologic treatment of reputed infectious causes, psychosocial and supportive therapies, and surgery to remove afflicted vestibular tissue.

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NVA Awards Record Number of Research Grants

Our summer 2006 research fundraiser was so successful that, this past fall, NVA funded three new vulvodynia research studies, in addition to supporting two ongoing studies from 2005. Because a huge number of scientists are competing for limited National Institutes of Health (NIH) funding, applicants find it advantageous to submit a sizable amount of preliminary data with their applications. Consequently, NVA's research grants can often play a critical role in helping scientists secure substantial long-term funding from the NIH.

Colin MacNeill, MD, associate professor of obstetrics and gynecology, Penn State Milton S. Hershey Medical Center, stated in his NVA research proposal that, "One key focus of vulvodynia research is understanding its pathophysiology, that is, the determination of cellular mechanisms by which chronic inflammation is initiated, and the genetic variants that encode proteins participating in this process." He proposes that, "an understanding of inflammatory mechanisms is an essential first step in designing effective therapies for vulvodynia and the paucity of such an understanding hampers design of effective treatments." Dr. MacNeill was awarded an NVA grant to determine the role of two collectins (proteins), Surfactant Protein-A (SP-A) and Surfactant Protein-D (SP-D), members of a family of innate immune pattern recognition proteins (immune system proteins that recognize disease-causing organisms), in regulating vulvovaginal inflammation. Surfactant proteins are produced in the vaginal and vestibular mucosa, as well as elsewhere in the body, and may play an important role in preventing vulvovaginal infection. Dr. MacNeill hypothesizes that polymorphisms (gene variants) that code for these proteins may be responsible for initiating or maintaining the early inflammatory process in Vulvar Vestibulitis Syndrome (VVS). In this study, he will test this hypothesis by measuring levels of surfactant proteins in vestibular tissue and testing for eleven polymorphisms in VVS patients and controls. In early 2007, Dr. MacNeill plans to include this data in a research application to the NIH.

Yitzchak Binik, PhD, professor of psychology at McGill University, was awarded an NVA grant to investigate the relationship between chronic Candida infection and Vulvar Vestibulitis Syndrome (VVS) in an animal model. Many women with VVS report previous recurrent episodes of vulvovaginal Candida infection. This association has led some researchers to

propose that chronic Candida infection, in which there is continued irritation of the vulvovaginal mucosa, may lead to the abnormal pain transmission experienced by women with VVS. In the present study, Dr. Binik will evaluate whether chronic Candida infection results in lowered vulvar pain thresholds and reduced mating behavior in mice. In addition, he will determine if the immunological profile associated with chronic Candida infection is similar to the immunological profile in VVS. Dr. Binik's goal is to use an animal model to pursue novel therapeutic interventions for women with vulvar pain.

Lori Boardman, MD, associate professor of obstetrics and gynecology at Brown University, Women and Infants' Hospital, was awarded a grant to conduct a Phase I study of the safety and tolerance of a novel topical treatment for VVS. Once this safety study is completed, she will submit the data in a research proposal to the NIH. This proposal will be to perform a multi-center, randomized, placebo-controlled clinical trial investigating the efficacy of this topical treatment.

Given the state of knowledge in the vulvodynia field, almost all of the research proposals submitted to NVA aim to investigate the cause(s) or treatments of Vulvar Vestibulitis Syndrome. It should be emphasized, however, that many clinicians and researchers have suggested that the results of VVS studies also are relevant to our understanding of generalized (or dysesthetic) vulvodynia.

The members of the NVA executive board would like to express their appreciation to everyone who contributed to the success of the 2006 research fundraiser. They would also like to thank the medical advisory board members and other vulvodynia experts who generously donated their time to review and score this year's research grant proposals. If you missed the opportunity and would like to make a donation to our 2007 *Medical Research Fund*, please contact Chris Veasley at chris@nva.org or Gigi Brecheen at gigi@nva.org or 301-949-5114.

(*Editor's Note: Thanks to the overwhelming generosity of individuals contacted in late November, the NVA Board has just awarded its first 2007 research grant to Dr. Steven Witkin of Weill Medical College of Cornell University. A summary of his research project will appear in our next newsletter.*) ■

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Symptom Relief

Applying topical anesthetic to the vestibule about 10 to 15 minutes prior to intercourse may relieve dyspareunia. A case report of a single patient described pain relief for 12 months after treatment with a 6-week course of submucosal infiltrations of betamethasone and lidocaine. Favorable results in 15 of 22 patients (either remission or marked improvement at 12- or 24-months of follow-up) were obtained with submucosal infiltrations of lidocaine and methylprednisolone. Presumably, such treatments combine immediate anesthetic effects as well as immediate and delayed anti-inflammatory or immunomodulating effects of the steroid.

Low-dose tricyclic antidepressants have been used based on their effectiveness in treating dysesthetic vulvodynia. These agents are indicated for pain reduction rather than for their effects on mood. In a series of 230 VVS patients, a 3- to 6-month course of low-dose amitriptyline resulted in a 60 percent positive response rate after 5 years of follow-up.

Biofeedback

Biofeedback is an appropriate conservative first choice in treatment. Two independent studies demonstrated the effectiveness of electromyographic biofeedback of the pelvic floor musculature in VVS patients with severe, chronic, introital dyspareunia. The therapy involves a program of in-home, biofeedback-assisted, pelvic-floor muscle rehabilitation exercises using portable equipment. Using resumption of sexual intercourse as a measure of treatment success, rates in the two studies were 78 percent and 89 percent, respectively.

Antifungal and Antiviral Agents

Historically, clinicians prescribed the oral antifungal fluconazole as a treatment, despite little evidence of efficacy, based on a presumptive association with *Candida* infection. In one of the few long-term, follow-up studies of this approach, maintenance antifungal therapy resulted in a 71 percent cure rate among women who had positive *Candida* cultures at initial diagnosis.

Injectable interferon- β and interferon- α have been

investigated with mixed results based on the presumptive association of VVS with HPV infection. Treatment appeared to be more effective in HPV-associated cases. Recent reports of a genetic deficiency in interferon- α production among some VVS patients have led to a resurgence of interest in therapy with exogenous interferon- α targeted at the appropriate subset of afflicted women.

Supportive and Multimodal Approaches

The comprehensive treatment of VVS should include some form of supportive therapy because it disrupts intimate relationships and causes great distress. Because of the intimate nature of their pain, many women delay seeking treatment; those who do are often frustrated and demoralized after appointments with multiple clinicians or after trying numerous interventions without success. Because of the significant impact of VVS on intimate relationships and psychological well-being, optimal treatment must address both its psychosexual and physical aspects. Clinicians must be willing to probe emotional and sexual concerns with sensitivity and be able to make referrals to mental health professionals, if necessary. Supportive psychosocial approaches, such as cognitive-behavioral sex therapy, can serve as adjunctive therapy. Some clinicians advocate integrated treatment programs consisting of physical therapy (including biofeedback), pain management and psychosexual support as the principal forms of intervention.

Surgery

Surgery is generally reserved for the most recalcitrant cases of VVS. The efficacy of surgical excision of painful vestibular tissue has been reviewed extensively elsewhere. Case series indicate that surgery is an effective form of therapy, with symptom relief in 60- to 90-percent of cases. It should be noted that the definition of a successful outcome, e.g., pain reduction or resumption of intercourse, varies among these studies and that most women serve as their own control.

The most conservative surgical technique, *vestibuloplasty*, involves vertical excision of the

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posterior vaginal introitus (vaginal entrance) without vaginal advancement. In partial *vestibulectomy*, the posterior portion of the vulvar vestibule is removed, with advancement of the vaginal epithelium to cover the excised portion. *Perineoplasty*, the most aggressive intervention, extends from just below the urethra to the fourchette (area beneath the vaginal opening where the labia minora meet); the vaginal epithelium is advanced laterally to the labia minora and posteriorly to the perineal body (area between anus and vaginal opening).

A small comparative study involving 21 women found that vestibuloplasty failed to relieve symptoms in 10 patients, while perineoplasty resulted in complete remission in 9 of 11 patients. In another study, removal of only the posterior vestibule (*vestibulectomy*), coupled with interferon treatment of the remaining anterior vestibule, was as effective as total perineoplasty and had fewer surgical complications. A 10-year retrospective chart review at the Mayo Clinic provided substantial evidence for the effectiveness of *vestibulectomy*, lending further support for this more conservative approach.

A partially randomized and nonrandomized study involving 48 women, comparing cognitive-behavioral therapy (CBT) and CBT preceded by *vestibulectomy*, found both treatments to be equally effective. Notably, although the study was to have been a randomized trial of CBT and surgery, it became difficult to continue assigning patients to surgery once it became apparent that the two treatments were equally effective; therefore, some patients were given the option of choosing surgical intervention prior to CBT. Because of the small group sizes (only 14 women participated in the randomized portion), the power of the statistical analysis and the study conclusions have been criticized.

A comparison of CBT, electromyographic biofeedback and *vestibulectomy* found that all treatments resulted in improvements in pain perception and sexual function at a 6-month follow-up, although *vestibulectomy* was significantly more successful. After two years, *vestibulectomy* remained superior in its impact on vestibular pain perception, but was no different to CBT specifically with regard to

pain with intercourse. It is unclear whether the duration of the physical and psychosocial interventions (12 weeks) was sufficient for an effective comparison of these alternative measures.

It should be noted that the data supporting the efficacy of surgery are not accepted universally. Some investigators have challenged study methodologies and the assumptions involved in measuring success rates; they believe that the psychosocial aspects of the syndrome are underappreciated and view surgery as unwarranted for a condition that has no clearly defined etiology.

Conclusion

VVS is a debilitating syndrome involving unexplained, localized vestibular pain on contact accompanied by minimal objective clinical findings. The etiology is unknown and possibly is multifactorial. The prevailing theory postulates that the syndrome is a neuropathic disorder of abnormal pain perception triggered by some form of chronic inflammation. Mounting evidence suggests that VVS-afflicted women are predisposed genetically to chronic inflammatory responses or may have impaired immune defenses against infectious agents. Evidence also exists that pelvic musculature dysfunction is a contributing factor. Rigorous randomized prospective trials evaluating alternative therapeutic approaches are lacking. Conservative interventions with some evidence for efficacy are anesthetic symptom relief, pain modulation with low-dose tricyclic antidepressants and electromyographic biofeedback. Antifungal or interferon therapy may be beneficial for selected subsets of patients. Surgical excision of afflicted portions of the vestibule produces relief but is reserved for chronic, recalcitrant cases when other treatments have failed. Patients with VVS benefit from supportive therapy; a multimodal treatment approach may be optimal to address both the physical symptoms and psychological consequences. More research is required to elucidate etiologic mechanisms and produce effective, evidence-based treatments for this complex disorder. ■

(Editor's note: To receive a copy of this article with footnotes and references, please contact Gigi Brecheen at gigi@nva.org or 301-949-5114.) ■

Sex Therapy

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in mind/body medicine have suggested that nearly all physical disorders have a psychological component, if only because having a disorder is, in and of itself, a life stressor (Walton & Thornton, 2003). In the case of vulvodynia, the neglect of psychological aspects, including sexual concerns, can prevent a woman from obtaining optimal relief for her condition.

Many vulvodynia sufferers are reluctant to choose the option of sex therapy because they have misconceptions about the treatment. Women, and possibly their partners, fear that they will be asked to disrobe in the therapy room or that there will be inappropriate touching. Other popular myths are that sex therapy consists of only a few old-fashioned exercises and that it ignores other aspects of a couples' relationship. In reality, sex therapy is simply a specialized type of psychotherapy in which the focus is on sexual function, including genital health and reproduction. Our purpose in writing this article is to provide readers with basic information about sex therapy and the treatment modalities that are commonly employed to optimize a woman's ability to cope and function, regardless of where she may be in terms of her medical treatment.

Assessment

Since a sex therapist is a licensed mental health professional (psychologist, marital therapist or social worker), the therapist takes a broad view of a person's presenting problem. Therefore, we begin with a general intake to gather information on a woman's background, e.g., family origin and psychological history. We assess women for depression, anxiety, pain disorders, distorted body image, relational problems and fertility issues, as well as substance and sexual abuse. Part of the reason for this in-depth assessment is to help the therapist make a judgment whether a referral to a psychiatrist might be appropriate as well. Once we have a sense of the woman as a whole, we conduct a detailed sexual health history.

Common Treatment Modalities

The comprehensive interview helps us understand the precise nature of the presenting problem and then we develop a treatment plan that includes some, or all, of the following interventions.

Individual Therapy

In individual treatment sessions, a woman usually relates an illness narrative to the therapist. It can be helpful to have a nonjudgmental, supportive therapist listen to a woman's description of her symptoms, her attempts to obtain a diagnosis, and how she finally obtained appropriate treatment. This process can help a woman integrate her experience, as well as voice her frustration, disappointment and fears, and even her hope. Sometimes women find that they have "worn out" even the most supportive families and friends, so having someone listen empathically can sometimes be healing in and of itself.

In individual treatment, a patient can also identify and explore prior issues such as sexual inhibitions generated by the beliefs of one's family, religion, or culture; sexual abuse or unhealthy sexual experiences such as being exposed to a parent's pornography; or mourning changes in one's body or sexual function. Underlying issues, such as depression or anxiety, are also generally best addressed in an individual context.

If the woman has a male partner, he may also benefit from individual sessions in which he can vent his own frustration and anger. Despite years of feminism, many men—even those who ostensibly believe in equality for women—may have a sense of entitlement about sex, or view sex as a genital activity rather than a pathway to physical and emotional intimacy. Men are often confused about their partner's diagnosis, some of them having bought into the "it's all in her head" adage. Receiving education about dyspareunia, vaginismus and other vulvar pain disorders can help the partner develop empathy and elicit his cooperation in treatment.

Couples Therapy

In our view, couples therapy is almost an imperative in the treatment of vulvodynia. Couples often have not sought treatment for years, and their sexual and intimate relationship has been disrupted by vulvodynia. Women often avoid all sexual contact (not just vaginal, but oral and manual) because sexual activity has become associated with pain; men, afraid of rejection,

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NVA Honors Executive Director's 10-Year Anniversary

In late October, co-workers and NVA Board members surprised Phyllis Mate, NVA's volunteer executive director, with a reception honoring her years of dedication to women with vulvodynia. The introductory speaker, Dr. Stanley Marinoff, NVA's first medical advisor and former director of the Center for Vulvovaginal Disorders in Washington, DC, spoke of NVA's remarkable growth under Phyllis' leadership. "Ten years ago this was a small group serving patients, but with Phyllis' vision, NVA has made an impact on Capitol Hill, convincing legislators to support NIH funding of research on the causes and treatments of vulvodynia." In addition, he noted that NVA raises funds to award grants for much-needed pilot studies and vulvar pain clinics.

NVA Treasurer Maurice Kreindler read a touching letter from Mona Schlossberg, who, in 1994, recognized the need to give women with vulvodynia a collective voice and generously donated the funds to create NVA. Mona wrote of Phyllis' commitment to educating the medical community. "She has led a successful campaign to raise awareness of vulvodynia among health care professionals. I have witnessed this in my own interactions with doctors. Finally, vulvodynia is out of the dark."

NVA co-founder Marjorie Veiga spoke of Phyllis' multi-tasking ability. "The executive director must supervise employees and volunteers, raise funds, and oversee all programs for patients and health care providers. At the same time, Phyllis burns the midnight oil editing our respected newsletter, read by thousands of physicians and patients in nine countries. She does this as a volunteer, sometimes working 60 hours a week."

Christin Veasley, director of professional programs, gave the evening's final tribute. She recalled Phyllis' kindness when she first contacted NVA as a teenager, shortly after being diagnosed with vulvodynia. "At a time when I had no hope, she answered the phone and provided the resources and support I needed to take back my life and go on to have the family I wanted." She described working closely with Phyllis for the past seven years, noting, "In a career where burn-out is common, she has shown me how to persevere and not get discouraged." Chris finished by turning to Phyllis and expressing the gratitude of women with vulvodynia, "Tonight, we honor you and all that you have sacrificed to make our lives better."

With co-founders Harriet O'Connor, Marjorie Veiga,

and Rhonda Brunell, Chris presented the honoree with a crystal vase inscribed, *In grateful appreciation of Phyllis Mate for ten years of exceptional service and dedication to the National Vulvodynia Association. Her vision, compassion and resolve have improved the lives of countless women with vulvodynia.* Upon accepting the award, Phyllis warmly acknowledged NVA staff members Chris Veasley, Gigi Brecheen, Judi Lenehan, and former support director, Harriet O'Connor, saying, "If it hadn't been for their help, I would have found a way to retire five years ago." Describing the journey from a small support group to an international patient advocacy organization, she reflected, "It's been enormously gratifying to see how the NVA's growth and influence led, not only to the first NIH vulvodynia conferences, but to federal funding of vulvodynia research." Phyllis characterized the success NVA has experienced during her tenure as a real-life example of the philosopher Johann Wolfgang von Goethe's aphorism, *At the moment of commitment, the universe conspires to assist you.* We're grateful she made that commitment. ■

ACOG Publishes Committee Opinion on Vulvodynia

In October 2006, the American College of Obstetricians and Gynecologists (ACOG), published a Committee Opinion on Vulvodynia in its clinical journal, *Obstetrics & Gynecology*, distributed to its 51,000 members. The Opinion will be included in the annual ACOG desk reference, a big step forward in educating *all* gynecologists about vulvodynia. NVA wishes to thank Ralph Hale, MD, ACOG's executive vice-president, for supporting educational initiatives that will heighten the profile of vulvodynia in the medical community, and recognizes the commitment of the late John Gibbons Jr, MD, who enthusiastically promoted this initiative.

Concurrent with the above publication, the NVA and the NIH Office of Research on Women's Health (ORWH) issued a joint media release. ORWH Director Vivian Pinn, MD, stated in the release, "Data from a recent NIH-funded study, conducted by Drs. Bernard Harlow and Elizabeth Stewart of Harvard University, show that 13 million women may suffer from vulvodynia during their lifetime. The data clearly demonstrate the need for continuing research on vulvodynia and for raising awareness about this condition among both women and their health care providers." ■

Sex Therapy

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stop seeking their partner (Kellogg-Spadt & Sernekos, 2003). With the disruption of sexual activity, there is often (though not always) a concomitant disruption in emotional intimacy (Binik, et al, 2002). Despite these disruptions, couples often report that they have a commitment to one another because of shared history, having children together, their religious beliefs, or other reasons. Finding the couples' unique strengths and using them to overcome obstacles to physical and emotional intimacy can help to re-establish their attachment bond. Finally, resuming a sexual relationship requires mutual cooperation, as at least some part of the intervention needs to be completed as a duo.

Education

A surprising number of women have misconceptions about their anatomy. As long as a medical diagnosis has already been established, we also use charts and models to show women and their partners how female reproductive anatomy and the pelvic floor are structured. Explanations and handouts can help women identify, for example, their pubococcygeus muscle and appropriate ways to exercise the muscle to facilitate successful intercourse, if this is the woman's or couple's goal. For some women, this level of intervention has proven adequate, but for others, a referral to a physical therapist specializing in pelvic floor work is definitely in order.

Sometimes couples, particularly young ones or those from less open cultures, have very little information regarding sexual behaviors such as foreplay. We treated a couple who, on their wedding night, literally walked out of a taxi, into a hotel room, and attempted intercourse for the first time without foreplay. This resulted in vaginismus, and thereafter, a year of painful attempts at intercourse and emotional tension. Sensate focus exercises or "nondemand pleasuring" exercises, as well as instruction about why foreplay is important in preparing the vagina for intercourse, are often the key to achieving a normal sexual life.

Additionally, education can be an important part of helping a woman and her partner gain new perspectives on sexual activity and encouraging them to explore possibilities both outside the bedroom—and outside of intercourse. Many times, couples stop being affectionate with each other because they are afraid

that affection will lead to intercourse, which they quite possibly have been trying to avoid. Educating patients directly about this common confusion of sex and affection can lead to a fruitful discussion of how to put affection back into their lives. Reminding couples there is more to sex than penis-vagina intercourse can be helpful, as is encouraging so-called "outercourse" such as manual and oral play. Finally, there are sex therapy exercises that can help a couple reconnect and re-educate them about the purpose of sexual activity, which is to express and receive love and caring through touch. The use of such exercises also can serve as "outercourse" when intercourse isn't possible.

In addition, we have had success with teaching women how to use vaginal dilators. Unlike a physical therapist, we cannot conduct such teaching *in vivo*, of course, but most women understand the concept of starting with the smallest dilator and learning to relax the pubococcygeus muscle. The benefit of learning within the context of psychotherapy is that you can also teach the patient to manage overall anxiety or anxiety about her body.

Pain Management

There are many pragmatic approaches to pain management that the sex therapist can employ to enhance medical treatment (Elliott, 2002). Several of these approaches utilize overall relaxation techniques, including progressive muscle relaxation, hypnosis and guided imagery. Biofeedback, such as heart rate variability biofeedback or galvanic skin response, can also help with overall relaxation and pain reduction. Part of the advantage of these techniques is that they give a woman a sense of control over her own physiological responses and improve her awareness of her body. Not all sex therapists will employ these techniques, but in our experience they can be a very useful part of treatment.

Coping Skills

Coping skills can be described as cognitive techniques or "self-talk" that help a person view the pain she is experiencing from a different perspective

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(Sharoff, 2004). Examples of self-talk that may be helpful are:

- Fighting pain makes it worse, and I accept that I have pain.
- There is pain; I will use my tools to help myself. I will do the best I can.
- It is no use being angry with my body. I will forgive myself and my body and I will practice kindness and tolerance towards myself.

Other coping skills include demonstrating assertiveness about one's needs; increasing self-care; finding multiple sources of pleasure outside of sexual activity; joining a group or a listserv for support; targeted reading; and so forth.

Case Study: Carla and Frank

Carla had been married a year when she contacted me because her husband was growing more and more frustrated with their almost complete lack of sexual activity. Carla explained that they were still married, only because she and her husband Frank were members of a fundamentalist religious group, and Frank was now insisting that they get help. Once in my office, Carla and her husband Frank struck me as unusually mature in their commitment to one another. Carla, a virgin on her wedding day, explained that their first attempt at intercourse on their honeymoon resulted in searing pain and tears. Subsequent attempts were very painful, leaving Carla sore, embarrassed, and even angry, so the couple decided to wait until they returned home to try intercourse again, thinking that the stress of the wedding and being in unfamiliar surroundings made it difficult for Carla to relax and enjoy the experience.

Unfortunately, that theory proved to be false. The barest touch of Frank's penis to Carla's vaginal opening made her eyes water with pain, and the few times Frank tried intercourse, penetration was so difficult that Frank decided, "It just wasn't worth it." Frank became increasingly irritable as Carla rejected even kissing or hugging, afraid it would ignite his desire for sex. When Frank told her it wasn't normal for a woman to refuse her husband's sexual advances and that she should submit to him, Carla said, "I lost it. I just couldn't believe he, of all people, could say something like that."

Still, Carla agreed that something was wrong. She visited a gynecologist, who, like her friends, told her that she needed to relax and perhaps take a warm bath or drink a glass of wine before trying to have sex. Carla related that the doctor never even mentioned the word vaginismus. I suggested that Carla seek a second opinion, this time from an urogynecologist who might be more familiar with vulvovaginal problems. I asked the couple to refrain from intercourse but permit affection and they agreed.

In the meantime, we worked on other aspects of the couple's sexual history, including how the topic of sexuality had been handled in each of their families. While Frank's family talked openly about sex, Carla reported that she had "no idea" what was going to happen on their wedding night and had been surprised by the entire experience. Because she had grown up in a religion that involved almost nightly attendance at services, she had little opportunity to interact with peers her own age and had no access to sexual information. We explored how their religious beliefs strengthened their relationship, because of the emphasis on commitment and approval of sexual pleasure within marriage. However, their religious background also left them unprepared for sexual intimacy by insulating them from sexual information.

Carla eventually met with the urogynecologist, who diagnosed idiopathic dyspareunia and prescribed lidocaine cream. She also recommended that Carla learn how to use vaginal dilators. Now that Carla had a diagnosis and treatment, she was motivated to have a healthy sexual life with her husband, if he changed his attitude. Frank agreed with Carla that he wasn't particularly sensitive when he made his "entitled" demand, but explained that he was so upset that he felt he had to do something to make a change. He agreed to be more sympathetic and patient.

Patience was definitely required. Although the lidocaine cream helped, Carla was very nervous about inserting the dilator. We worked on her thought processes that seemed to fuel her anxiety, examining her ideas about performance, both in and out of the bedroom. I also taught her biofeedback, which helped her recognize the differences in her body when she was

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tense versus relaxed. Although Carla's religion forbade the use of hypnosis, she was comfortable imagining her vaginal muscles softening and yielding to the dilators. Learning how to relax and tense her Kegel muscles also helped greatly, and eventually Carla was able to insert the smallest dilator with little difficulty. I also recommended books the couple could read on vulvodynia and sexuality in general.

It took many weeks until Carla was able to fully insert the largest dilator. Then we discussed different lovemaking positions that the couple could try in attempting intercourse. I suggested that the position with the woman on top would give Carla more control over penetration. They began sensate focus exercises and found that these helped them understand lovemaking and made them feel more confident in their ability to try intercourse again.

At this point, Carla and Frank made a surprise announcement that they were taking an extended vacation and would not be coming in for several weeks. Because their trip would be like another honeymoon, I explored their expectations for sexual activity while they were away. Frank expressed optimism that they would be able to have sex, but Carla wasn't so sure. She was going to take the dilators with her and was willing to be intimate with Frank if he wanted to experience sexual pleasure. We explored why she was more concerned with Frank's pleasure than her own, and a light seemed to go on. "I never thought about it, but I guess maybe I've always thought of sex as my 'duty'. That doesn't sound like much fun, does it?" I shook my head and encouraged her to give herself permission to have whatever pleasure she could, whether it was from intercourse or sexual play.

After their trip, they cancelled their first therapy appointment. Concerned that things had gone awry, I called Carla, who reported that they were, in fact, doing very well. Their first few attempts "weren't very good," Carla reported. "We barely did anything, but we were having such a wonderful time together and I guess I was able to focus on my feelings about Frank instead of my fears." Carla told me that she and Frank had decided that therapy was no longer necessary and wanted to terminate treatment. I agreed, but let Carla know that they could return at any time.

Finding a Sex Therapist

Sex therapy is an excellent adjunct to the medical treatment of vulvodynia. Not all sex therapists have an interest in treating this disorder, however, so it is best to search for someone with the appropriate training. To find a trained sex therapist, the best resource is the American Association of Sexuality Educators, Counselors, and Therapists (AASECT) at www.aasect.org. If there is not a certified sex therapist in your area listed on the website, contact AASECT via phone to find an uncertified sex therapist that has the appropriate training. Another resource is your medical doctor or gynecologist, who may know a psychotherapist who treats sexual problems, but is not an AASECT member.

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- (Editor's Note: If you would like to receive a copy of this article with a complete list of references, please contact Gigi Brecheen at gigi@nva.org or 301-949-5114.)* ■